



# Exposure and Disease Registries

## WHAT IS THE PUBLIC HEALTH ISSUE?

- About 40,000 hazardous waste sites have been reported to the federal government. Additionally, there are thousands of unplanned releases of toxins into the environment each year.
- More than 1,600 hazardous waste sites are included on the National Priorities List (NPL) and are targeted for clean up by the Environmental Protection Agency. About 15 million people live within 1 mile of NPL sites.
- Exposure registries offer a way to catalog health effects that might be associated with exposure to substances.

## WHAT HAS ATSDR ACCOMPLISHED?

The Agency for Toxic Substances and Disease Registry (ATSDR) created three types of registries: the World Trade Center Health Registry (WTCHR), the Tremolite Asbestos Registry (TAR) and the National Exposure Registry (NER), all of which records and follows reported health information from persons with documented exposures.

ATSDR and the New York City Department of Health and Mental Hygiene developed the World Trade Center Health Registry in 2003, which follows the health of persons most exposed to the events and aftermath of the September 11, 2001, attack. The WTCHR completed interviews of people in the damaged or destroyed buildings; residents and school children in lower Manhattan; and rescue recovery workers. Completing 71,437 interviews made the WTCHR the largest registry of its kind in the history of the United States.

In 2000 and 2001, the Agency for Toxic Substances and Disease Registry (ATSDR) provided free screening to persons with potential exposure to asbestos-contaminated vermiculite in Libby. 7,307 persons received this screening. In 2003, ATSDR provided a grant to the Montana Department of Public Health and Human Services to create a program providing additional baseline and follow-up screening. This program is named the Montana Asbestos Screening and Surveillance Activity (MASSA). At the same time, MASSA began enrolling program participants in ATSDR's Tremolite Asbestos Registry (TAR). Additional subjects were enrolled in the TAR in 2004 when ATSDR conducted telephone interviews of persons for whom an abnormality was detected in the 2000/2001 screening and persons who were eligible to take part in the screening effort but were unable to get to Libby. The MASSA completed 2,208 interviews and the TAR completed 1,805 interviews.

The National Exposure Registry started in 1989 and was designed to aid in assessing the long-term health consequences of low-level, long-term exposures to hazardous chemicals identified at hazardous waste sites. The NER consists of four established registries: Trichloroethylene, Dioxin, Trichloroethane, and Benzene. At the baseline interview we have 12,428 completed interviews. Registrants on all four registries have reported increases of such problems as anemia, other blood disorders, and urinary tract disorders. Other conditions that appear on at least three of the registries include skin rashes, eczema, other skin allergies, and stroke.

ATSDR shares registry information with participants so that they can make informed decisions about their health. ATSDR also analyzes information gathered from the exposure registries to identify opportunities for future health studies.

## WHAT ARE THE NEXT STEPS?

ATSDR is investigating the formation of disease registries to facilitate the identification and evaluation of specific health outcomes (e.g., multiple sclerosis, Parkinson disease) that might be associated with exposure to hazardous substances in the environment. ATSDR will continue with follow-up interviews with the TAR and WTCHR to track long-term effects. ATSDR will strengthen its collaborations with the Pew Environmental Health Commission and other public health professionals to offer solutions to surveillance challenges cited in Pew's 2000 report, *America's Environmental Health Gap*.

For information on this and other CDC and ATSDR programs, visit [www.cdc.gov/programs](http://www.cdc.gov/programs).

December 2004